

105TH CONGRESS
1ST SESSION

S. 89

To prohibit discrimination against individuals and their family members on the basis of genetic information, or a request for genetic services.

IN THE SENATE OF THE UNITED STATES

JANUARY 21, 1997

Ms. SNOWE introduced the following bill; which was read twice and referred to the Committee on Labor and Human Resources

A BILL

To prohibit discrimination against individuals and their family members on the basis of genetic information, or a request for genetic services.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Genetic Information
5 Nondiscrimination in Health Insurance Act of 1997”.

6 **SEC. 2. AMENDMENTS TO EMPLOYEE RETIREMENT INCOME**
7 **SECURITY ACT OF 1974.**

8 (a) IN GENERAL.—Subpart B of part 7 of subtitle
9 B of title I of the Employee Retirement Income Security

1 Act of 1974 is amended by inserting after section 712 the
 2 following:

3 **“SEC. 713. PROHIBITION OF HEALTH INSURANCE DISCRIMI-**
 4 **NATION ON THE BASIS OF GENETIC INFOR-**
 5 **MATION.**

6 “(a) IN GENERAL.—In the case of benefits consisting
 7 of medical care provided under a group health plan or in
 8 the case of group health insurance coverage offered by a
 9 health insurance issuer in connection with a group health
 10 plan, the plan or issuer may not deny, cancel, or refuse
 11 to renew such benefits or such coverage, or vary the pre-
 12 miums, terms, or conditions for such benefits or such cov-
 13 erage, for any participant or beneficiary under the plan—

14 “(1) on the basis of genetic information; or

15 “(2) on the basis that the participant or bene-
 16 ficiary has requested or received genetic services.

17 “(b) LIMITATION ON COLLECTION AND DISCLOSURE
 18 OF INFORMATION.—

19 “(1) IN GENERAL.—A group health plan, or a
 20 health insurance issuer offering group health insur-
 21 ance coverage in connection with a group health
 22 plan, may not request or require a participant or
 23 beneficiary (or an applicant for coverage as a partic-
 24 ipant or beneficiary) to disclose to the plan or issuer

1 genetic information about the participant, bene-
 2 ficiary, or applicant.

3 “(2) REQUIREMENT OF PRIOR AUTHORIZA-
 4 TION.—A group health plan, or a health insurance
 5 issuer offering health insurance coverage in connec-
 6 tion with a group health plan, may not disclose ge-
 7 netic information about a participant or beneficiary
 8 (or an applicant for coverage as a participant or
 9 beneficiary) without the prior written authorization
 10 of the participant, beneficiary, or applicant or of the
 11 legal representative thereof. Such authorization is
 12 required for each disclosure and shall include an
 13 identification of the person to whom the disclosure
 14 would be made.

15 “(c) DEFINITIONS.—For purposes of this section—

16 “(1) GENETIC INFORMATION.—The term ‘ge-
 17 netic information’ means information about genes,
 18 gene products, or inherited characteristics that may
 19 derive from an individual or a family member of the
 20 individual.

21 “(2) GENETIC SERVICES.—The term ‘genetic
 22 services’ means health services provided to obtain,
 23 assess, and interpret genetic information for diag-
 24 nostic and therapeutic purposes, and for genetic
 25 education and counselling.

1 “(3) FAMILY MEMBER.—The term ‘family
2 member’ means, with respect to an individual, an-
3 other individual related by blood to that individual,
4 or a spouse or adopted child of the individual.”.

5 (b) DAMAGES.—Section 502(c) of such Act (29
6 U.S.C. 1132(c)) is amended by adding at the end the fol-
7 lowing:

8 “(7) Any group health plan (as defined in section
9 733(a)) and any health insurance issuer (as defined in sec-
10 tion 733(b)(2)) who fails to meet the requirements of sec-
11 tion 713 with respect to any participant, beneficiary, or
12 applicant referred to in such section may in the court’s
13 discretion be liable to such participant, beneficiary, or ap-
14 plicant for compensatory, consequential, and punitive
15 damages.”.

16 (c) CLERICAL AMENDMENT.—The table of contents
17 in section 1 of such Act is amended by inserting after the
18 item relating to section 712 the following:

“Sec. 713. Prohibition of health insurance discrimination on the basis of genetic
information.”.

19 (d) EFFECTIVE DATE.—The amendments made by
20 this section shall apply with respect to group health plans
21 for plan years beginning after 1 year after the date of
22 the enactment of this Act.

1 **SEC. 3. AMENDMENTS TO THE PUBLIC HEALTH SERVICE**
 2 **ACT.**

3 (a) AMENDMENT RELATING TO THE GROUP MAR-
 4 KET.—

5 (1) IN GENERAL.—Subpart 2 of part A of title
 6 XXVII of the Public Health Service Act is amended
 7 by inserting after section 2705 the following:

8 **“SEC. 2706. PROHIBITION OF HEALTH INSURANCE DIS-**
 9 **CRIMINATION ON THE BASIS OF GENETIC IN-**
 10 **FORMATION.**

11 “(a) IN GENERAL.—In the case of benefits consisting
 12 of medical care provided under a group health plan or in
 13 the case of group health insurance coverage offered by a
 14 health insurance issuer in connection with a group health
 15 plan, the plan or issuer may not deny, cancel, or refuse
 16 to renew such benefits or such coverage, or vary the pre-
 17 miums, terms, or conditions for such benefits or such cov-
 18 erage, for any participant or beneficiary under the plan—

19 “(1) on the basis of genetic information; or

20 “(2) on the basis that the participant or bene-
 21 ficiary has requested or received genetic services.

22 “(b) LIMITATION ON COLLECTION AND DISCLOSURE
 23 OF INFORMATION.—

24 “(1) IN GENERAL.—A group health plan, or a
 25 health insurance issuer offering group health insur-
 26 ance coverage in connection with a group health

1 plan, may not request or require a participant or
 2 beneficiary (or an applicant for coverage as a partic-
 3 ipant or beneficiary) to disclose to the plan or issuer
 4 genetic information about the participant, bene-
 5 ficiary, or applicant.

6 “(2) REQUIREMENT OF PRIOR AUTHORIZA-
 7 TION.—A group health plan, or a health insurance
 8 issuer offering health insurance coverage in connec-
 9 tion with a group health plan, may not disclose ge-
 10 netic information about a participant or beneficiary
 11 (or an applicant for coverage as a participant or
 12 beneficiary) without the prior written authorization
 13 of the participant, beneficiary, or applicant or of the
 14 legal representative thereof. Such authorization is
 15 required for each disclosure and shall include an
 16 identification of the person to whom the disclosure
 17 would be made.

18 “(c) DEFINITIONS.—For purposes of this section—

19 “(1) GENETIC INFORMATION.—The term ‘ge-
 20 netic information’ means information about genes,
 21 gene products, or inherited characteristics that may
 22 derive from an individual or a family member of the
 23 individual.

24 “(2) GENETIC SERVICES.—The term ‘genetic
 25 services’ means health services provided to obtain,

1 assess, and interpret genetic information for diag-
 2 nostic and therapeutic purposes, and for genetic
 3 education and counselling.

4 “(3) FAMILY MEMBER.—The term ‘family
 5 member’ means, with respect to an individual, an-
 6 other individual related by blood to that individual,
 7 or a spouse or adopted child of the individual.”.

8 (2) EFFECTIVE DATE.—The amendment made
 9 by this subsection shall apply with respect to group
 10 health plans for plan years beginning after 1 year
 11 after the date of the enactment of this Act.

12 (b) AMENDMENT RELATING TO THE INDIVIDUAL
 13 MARKET.—

14 (1) IN GENERAL.—Subpart 3 of part B of title
 15 XXVII of such Act is amended by inserting after
 16 section 2751 the following:

17 **“SEC. 2752. PROHIBITION OF HEALTH INSURANCE DIS-**
 18 **CRIMINATION ON THE BASIS OF GENETIC IN-**
 19 **FORMATION.**

20 “The provisions of section 2705 shall apply to health
 21 insurance coverage offered by a health insurance issuer
 22 in the individual market in the same manner as it applies
 23 to health insurance coverage offered by a health insurance
 24 issuer in connection with a group health plan in the small
 25 or large group market.”.

1 (2) EFFECTIVE DATE.—The amendment made
 2 by this subsection shall apply with respect to health
 3 insurance coverage offered, sold, issued, renewed, in
 4 effect, or operated in the individual market after 1
 5 year after the date of the enactment of this Act.

6 (c) ACTION FOR DAMAGES.—Section 2761 of such
 7 Act (29 U.S.C. 300gg–61) is amended by adding at the
 8 end the following:

9 “(c) ACTION FOR DAMAGES

10 “(1) IN GENERAL.—In any case in which a
 11 group health plan or a health insurance issuer fails
 12 to meet the applicable requirements of section 2706
 13 or 2752 with respect to any individual who is a plan
 14 participant or beneficiary in such a plan, a covered
 15 individual, or an applicant for coverage, such indi-
 16 vidual may bring a civil action under this section. In
 17 any such action, such plan or issuer may in the
 18 court’s discretion be liable to such individual for
 19 compensatory, consequential, and punitive damages.

20 “(2) ADDITIONAL PROVISIONS.—For purposes
 21 of this subsection, the provisions of subsections (d),
 22 (e), (f), (g), (h), and (j) of section 502 of the Em-
 23 ployee Retirement Income Security Act of 1974 shall
 24 apply in connection with such action, the plaintiff in
 25 such action, and the Secretary of Health and

1 Human Services in the same manner and to the
 2 same extent as such provisions apply in connection
 3 with actions under such section 502, plaintiffs in
 4 such actions, and the Secretary of Labor.”.

5 **SEC. 4. AMENDMENTS TO TITLE XVIII OF THE SOCIAL SE-**
 6 **CURITY ACT RELATING TO MEDIGAP.**

7 (a) IN GENERAL.—Section 1882(s)(2) of the Social
 8 Security Act (42 U.S.C. 1395ss(s)) is amended by adding
 9 at the end the following:

10 “(D)(i) An issuer of a medicare supplemental policy
 11 (as defined in section 1882(g)) may not deny or condition
 12 the issuance or effectiveness of the policy, and may not
 13 discriminate in the pricing of the policy of an eligible indi-
 14 vidual—

15 “(I) on the basis of genetic information; or

16 “(II) on the basis that the individual or a fam-
 17 ily member of the individual has requested or re-
 18 ceived genetic services.

19 “(ii) For purposes of this subparagraph—

20 “(I) The term ‘genetic information’ means in-
 21 formation about genes, gene products, or inherited
 22 characteristics that may derive from an individual or
 23 a family member of the individual.

1 “(II) The term ‘genetic services’ means health
 2 services provided to obtain, assess, and interpret ge-
 3 netic information for diagnostic and therapeutic pur-
 4 poses, and for genetic education and counselling.

5 “(III) The term ‘family member’ means, with
 6 respect to an individual, another individual related
 7 by blood to that individual, or a spouse or adopted
 8 child of the individual.”.

9 (b) ACTION FOR DAMAGES.—Section 1882(s) of the
 10 Social Security Act (42 U.S.C. 1395ss(s)) is amended fur-
 11 ther by adding at the end the following:

12 “(4)(A) In any case in which a medicare supple-
 13 mental policy fails to meet the applicable requirements of
 14 paragraph (2)(D) with respect to any individual who is
 15 a covered individual or an applicant for coverage, such in-
 16 dividual may bring a civil action under this paragraph. In
 17 any such action, the issuer of such policy may in the
 18 court’s discretion be liable to such individual for compen-
 19 satory, consequential, and punitive damages.

20 “(B) For purposes of this paragraph, the provisions
 21 of subsections (d), (e), (f), (g), (h), and (j) of section 502
 22 of the Employee Retirement Income Security Act of 1974
 23 shall apply in connection with such action, the plaintiff
 24 in such action, and the Secretary of Health and Human
 25 Services in the same manner and to the same extent as

1 such provisions apply in connection with actions under
 2 such section 502, plaintiffs in such actions, and the Sec-
 3 retary of Labor.”.

4 (c) EFFECTIVE DATE.—The amendments made by
 5 this section shall apply with respect to medicare supple-
 6 mental policies offered, sold, issued, renewed, in effect, or
 7 operated in the individual market after 1 year after the
 8 date of the enactment of this Act.

9 **SEC. 5. AMENDMENTS OF INTERNAL REVENUE CODE OF**
 10 **1986.**

11 (a) IN GENERAL.—Chapter 100 of the Internal Reve-
 12 nue Code of 1986 (relating to group health plan port-
 13 ability, access, and renewability requirements) is amended
 14 by adding at the end the following:

15 **“Subchapter B—Prohibition of Discrimina-**
 16 **tion By Group Health Plans on Basis of**
 17 **Genetic Information**

“Sec. 9811. Prohibition of discrimination by group health plans
 on basis of genetic information.

18 **“SEC. 9811. PROHIBITION OF DISCRIMINATION BY GROUP**
 19 **HEALTH PLANS ON BASIS OF GENETIC IN-**
 20 **FORMATION.**

21 “(a) IN GENERAL.—In the case of benefits consisting
 22 of medical care provided under a group health plan or in
 23 the case of group health insurance coverage offered by a
 24 health insurance issuer in connection with a group health

1 plan, the plan or issuer may not deny, cancel, or refuse
 2 to renew such benefits or such coverage, or vary the pre-
 3 miums, terms, or conditions for such benefits or such cov-
 4 erage, for any participant or beneficiary under the plan—

5 “(1) on the basis of genetic information; or

6 “(2) on the basis that the participant or bene-
 7 ficiary has requested or received genetic services.

8 “(b) LIMITATION ON COLLECTION AND DISCLOSURE
 9 OF INFORMATION.—

10 “(1) IN GENERAL.—A group health plan, or a
 11 health insurance issuer offering group health insur-
 12 ance coverage in connection with a group health
 13 plan, may not request or require a participant or
 14 beneficiary (or an applicant for coverage as a partic-
 15 ipant or beneficiary) to disclose to the plan or issuer
 16 genetic information about the participant, bene-
 17 ficiary, or applicant.

18 “(2) REQUIREMENT OF PRIOR AUTHORIZA-
 19 TION.—A group health plan, or a health insurance
 20 issuer offering health insurance coverage in connec-
 21 tion with a group health plan, may not disclose ge-
 22 netic information about a participant or beneficiary
 23 (or an applicant for coverage as a participant or
 24 beneficiary) without the prior written authorization
 25 of the participant, beneficiary, or applicant or of the

1 legal representative thereof. Such authorization is
 2 required for each disclosure and shall include an
 3 identification of the person to whom the disclosure
 4 would be made.

5 “(c) DEFINITIONS.—For purposes of this section—

6 “(1) GENETIC INFORMATION.—The term ‘ge-
 7 netic information’ means information about genes,
 8 gene products, or inherited characteristics that may
 9 derive from an individual or a family member of the
 10 individual.

11 “(2) GENETIC SERVICES.—The term ‘genetic
 12 services’ means health services provided to obtain,
 13 assess, and interpret genetic information for diag-
 14 nostic and therapeutic purposes, and for genetic
 15 education and counselling.

16 “(3) FAMILY MEMBER.—The term ‘family
 17 member’ means, with respect to an individual, an-
 18 other individual related by blood to that individual,
 19 or a spouse or adopted child of the individual.”.

20 (b) TECHNICAL AND CONFORMING AMENDMENTS.—

21 (1) Paragraph (1) of section 4980D(f) of such
 22 Code (relating to failure to meet certain group
 23 health plan requirements) is amended by adding at
 24 the end the following new sentence: “For purposes

1 of applying this section with respect to the require-
 2 ments of subchapter B of chapter 100, the term
 3 ‘group health plan’ includes a health insurance is-
 4 suer (within the meaning of section 9811).”

5 (2) Chapter 100 of such Code is amended by
 6 striking the chapter heading and inserting the fol-
 7 lowing:

8 **“CHAPTER 100—REQUIREMENTS RELAT-**
 9 **ING TO GROUP HEALTH PLANS, ETC.**

“SUBCHAPTER A. Group health plan portability, access, and re-
 newability requirements.

“SUBCHAPTER B. Prohibition of discrimination by group health
 plans on basis of genetic information.

10 **“Subchapter A—Group Health Plan Port-**
 11 **ability, Access, and Renewability Re-**
 12 **quirements”.**

13 (3) The table of chapters for such Code is
 14 amended by striking the item relating to chapter
 15 100 and inserting the following:

“CHAPTER 100. Requirements relating to group health plans,
 etc.”

16 (4) Subsection (a) of section 4980D of such
 17 Code is amended by striking “(relating to group
 18 health plan portability, access, and renewability re-
 19 quirements)” and inserting “(relating to group
 20 health plans, etc., requirements)”.

21 (c) EFFECTIVE DATE.—The amendments made by
 22 this section shall apply with respect to group health plans

- 1 for plan years beginning after 1 year after the date of
- 2 the enactment of this Act.

